

# Budget Unit Brief

## FY 2017



## Congenital and Inherited Disorders Registry

### History and Purpose

The [Iowa Department of Public Health](#) (DPH) is required to develop and administer the state's policy with respect to the conduct of scientific investigations and research concerning the causes, prevention, treatment, and cure of birth defects. The [Center for Congenital and Inherited Disorders](#) was established in 1976 to initiate, conduct, and supervise genetic investigations and research to provide for the protection and promotion of the health of Iowans. Since its creation, the Center for Congenital and Inherited Disorders, in partnership with the University of Iowa (UI) and health care providers throughout the state, has developed programs that have provided Iowa with state of the art genetics health care. The programs of the Center for Congenital and Inherited Disorders address all steps of the life cycle: prenatal, neonatal, pediatric, and adult.

There are seven programs within the Center for Congenital and Inherited Disorders which include: the [Regional Genetic Consultation Service \(RGCS\)](#), the [Iowa Newborn Screening Program \(INSP\)](#), the [Maternal and Prenatal Screening](#), the [Iowa Registry for Congenital and Inherited Disorders](#), the [Neuromuscular and Related Genetic Disorders Program \(NMP\)](#), the [Iowa Early Hearing Detection and Intervention \(EHDI\)](#), and the [Stillbirth Surveillance and Prevention Program](#).

Established within the Center for Congenital and Inherited Disorders is the [Congenital and Inherited Disorders Advisory Committee \(CIDAC\)](#). This Committee acts in an advisory capacity to the programs of the Center. The Committee is composed of representatives from each of the programs, various professional health care groups, consumers, two legislators, and a representative of the DPH.

The [Registry for Congenital and Inherited Disorders](#) is the reporting system to identify and monitor birth defects and stillbirths in the state of Iowa. Birth defects and stillbirths are reportable conditions in Iowa and the records of these birth defects and stillbirths are abstracted and maintained. The registry was established in 1983 through the joint efforts of the University of Iowa, the Iowa Department of Public Health, and the Iowa Department of Human Services. The Program is located within the [College of Public Health at the University of Iowa](#). The mission of the Iowa Registry for Congenital and Inherited Disorders is to:

- Maintain statewide surveillance for collecting information on birth defects and stillbirth occurrence;
- Monitor annual trends in birth defects and stillbirth occurrence and mortality;
- Conduct research to identify genetic and environmental risk factors for birth defects and stillbirths; and
- Promote educational activities for the prevention of birth defects and stillbirths.

### Funding — State General Fund

There is a standing unlimited appropriation in Iowa Code section [144.13A\(4\)\(b\)](#) from the General Fund that permits the DPH to retain \$10 of the \$20 Birth Certificate Registration Fee for the registry. This amount has been approximately \$199,000 annually over the past five years. The other \$10 is appropriated for the [Child Abuse Prevention Program Administration](#).

There are allocations from the General Fund [Chronic Conditions](#) and the [Healthy Children and Families](#) appropriations to the DPH for programs in the Center for Congenital and Inherited Disorders. Additionally, there is a General Fund appropriation to the UI for the [Iowa Birth Defects Registry](#) annually in the Education Appropriations Act.

### Related Statutes and Administrative Rules

Iowa Code chapter [136A](#) and section [144.13A\(4\)\(a\)](#)  
[641](#) Iowa Administrative Code chapter [4.7](#)

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### More Information

Center for Congenital and Inherited Disorders: <http://idph.iowa.gov/genetics>

Iowa General Assembly: <https://www.legis.iowa.gov/>

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